

BRIEF REPORTS

Ground Realities of Autism Spectrum Disorders in Sri Lanka

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ABSTRACT

Autism spectrum disorders (ASD) are a group of developmental disabilities that impact children and adults globally. The majority of children diagnosed with ASD live in low- and middle-income countries (LMICs). There is, however, inadequate understanding of the prevalence, screening, diagnosis and treatment for these children in LMICs. As most of the current evidence comes from high-income countries, this narrative review will focus specifically on children with ASD living in Sri Lanka, a lower-middle-income country. It will discuss the prevalence of ASD, current screening and diagnostic assessments, and services available for these children, with a focus on speech therapy and augmentative and alternative communication (AAC).

Key words: *Autism Spectrum Disorders (ASD), Low- and Middle-Income Countries (LMICs), Augmentative and Alternative Communication (AAC), Avaz Sri Lanka*

Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) are a group of developmental disabilities that occur in children, regardless of race or ethnicity. It is a condition that not just low- and middle-income countries (LMICs) struggle with, but also economically advantaged countries (Elsabbagh et al., 2012). The two main aspects impacted in ASD are social communication deficits and restricted and repetitive behaviours (American Psychiatric Association, 2013).

Global Prevalence of ASD

Global estimates of ASD vary among different countries. The most recent estimates from the United States report prevalence rates as high as 1 in 54 children

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(Maenner et al., 2020). Specific estimates of children with ASD living in LMICs are scarce. In general, an estimated 85% of children with disabilities live in LMICs (Helander, 1993); however, these very same countries are under-represented in research conducted on autism (Durkin et al., 2015). Epidemiological data with regard to prevalence of ASD is essential for policy decisions and to strengthen public health practices and services (Elsabbagh et al., 2012).

Prevalence of ASD in Sri Lanka

Sri Lanka has been classified as a lower-middle-income country (The World Bank, 2020). Currently there are only a handful of published and unpublished studies that provide a limited glimpse into ASD and the special education system in Sri Lanka (e.g., Muttiah, Drager, & O'Connor, 2016; Perera, Wijewardena, & Aluthwelage, 2009). To date, only one published study conducted in Sri Lanka gives estimates of the number of children with ASD in the country. It reports a prevalence rate of 10.7 per 1000 children or 1 in 93 children being identified as having ASD (Perera et al., 2009). This is probably a gross underestimation of the actual numbers, as the method used to establish the prevalence rate consisted of a screening tool. In addition, there is evidence referring to the fact that missed or delayed diagnosis of ASD is more prevalent among ethnic and racially diverse groups (Mandell et al., 2009).

Screening for ASD

The American Association of Paediatrics (AAP) has issued a statement that, in general, developmental screenings should be conducted at 9, 18, and 30-month visits, and specific screenings for ASD should be done at 18 and 24 months of age (Hyman, Levy, & Myers, 2020). However, in many LMICs such as Sri Lanka, conducting routine screenings for ASD, as recommended by the AAP, can be complicated for a multitude of reasons. First, agreeing on what types of behavioural characteristics to include in a screening tool is a challenge, as the recognition of a certain behaviour being a deficit can vary among cultures (Wallis & Pinto-Martin, 2008). For example, in a study conducted in Sri Lanka, parents' primary concern was poor development of speech (Perera, Jeewandara, Guruge, & Seneviratne, 2013). Only a small percentage of Sri Lankan parents were concerned about their children's social impairments. In addition, only a small number recognised repetitive, stereotyped behaviours. Secondly, it may not always be appropriate to adapt a screening tool that has been developed in one culture for use by another

(Wallis & Pinto-Martin, 2008). This was evidenced by the translation and use of the Modified-Checklist for Autism in Toddlers (M-CHAT), a screening tool for young children between 18 and 24 months of age. The M-CHAT was translated into Sinhala (the main local language spoken in Sri Lanka). Perera and colleagues (2009) found that when the M-CHAT was used with a group of children in Sri Lanka, it was only 25% sensitive to detect ASD. As a result of the outcomes of this study, a follow-up study was conducted with a view to designing a pictorial screening tool (Perera et al., 2013). The Pictorial Autism Assessment Schedule used photographs to better illustrate the questions that were asked in the checklist. The checklist of items was adapted from the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), M-CHAT, and "First Signs" from the American Academy of Neurology and the Child Neurology Society. Cultural adaptations were also taken into consideration when developing the tool. Hence, the photographs were of local Sri Lankan children and the items in the checklist were directly written in the local language (Sinhala) rather than translating them from English. The sensitivity of this tool in discriminating between ASD and non-ASD was 88%. However this tool has not been validated, which makes it difficult to use nationally as a screening tool for ASD.

Diagnostic Assessments for ASD

Currently, there are no standardised, norm-referenced ASD diagnostic tools to identify children with ASD in Sri Lanka. The gold standard for diagnosing ASD globally is the Autism Diagnostic Observation Schedule (ADOS-2) (Gotham, Risi, Pickles, Lord, 2006). Clinicians who conduct the ADOS-2 have to be certified and need access to the diagnostic kit with standardised materials. In Sri Lanka, there are less than a handful of professionals certified to conduct the ADOS-2. Both the certification process and the ADOS-2 diagnostic kit are expensive. In addition, some of the items and materials in the ADOS are not culturally and linguistically appropriate. For example, one of the tasks in the Toddler module involves bathing a doll in a bathtub. Many toddlers in Sri Lanka do not have access to a bathtub and are not used to playing with toys while having a bath.

Services

Screening and diagnostic tools to identify the number of children with ASD are useful only if there are corresponding services to support the children identified. In theory, in Sri Lanka, children with ASD have access to speech therapy,

occupational therapy, psychological, and educational services. However, the reality is that these services are only available at larger, urban hospitals in the country. Children living in more rural areas would have to travel to the bigger cities to access such services. Speech therapy has been identified as an essential service for children diagnosed with ASD due to social communication deficits being one of the core deficits (American Psychiatric Association, 2013).

Speech Therapy Services

Speech-Language Pathology is a relatively new profession in Sri Lanka. The first batch of undergraduate speech therapists enrolled in 2008 and graduated in 2012. Currently, approximately 151 Speech-Language Pathologists (SLPs) have been licensed and registered in a country of 20.4 million people (N.R. De Silva, personal communication, August 13, 2018). This indicates that there is approximately one SLP for every 135,000 citizens. This highlights the limited number of professionals who are attempting to provide services to a significant number of children. Professionals are consequently overwhelmed and unable to provide adequate, quality services to all individuals who need them. This has led to the need for innovating methods to provide children and families better access to services. Perera and colleagues reported on a home-based intervention programme that they conducted to deal with this very problem (Perera, Jeewandara, Seneviratne, & Guruge, 2016). Parents were trained on structured play activities and activities to promote joint attention during everyday tasks (e.g., mealtimes). The results indicated positive gains in the children, particularly in the first 3 months after intervention. The findings of this study provide some preliminary evidence in favour of implementing these types of home-based interventions in low-resource settings similar to Sri Lanka.

Augmentative and Alternative Communication (AAC) in Sri Lanka

It is estimated that one-third to half of the children with ASD do not use speech functionally (National Research Council, 2001). Therefore, many of these individuals would benefit from AAC to support their current speech or to act as their primary method of communication (Mirenda, 2003). AAC includes aided technologies, both low (e.g., picture boards, communication books) and high (e.g., speech generating devices, mobile devices), as well as unaided forms of communication (e.g., signs, gestures) (Beukelman & Mirenda, 2013). In countries where there are a limited number of SLPs, the number of skilled professionals

specialising in AAC is extremely small (Fuller et al, 2009). In addition, having culturally and linguistically appropriate AAC options are essential for children with communication difficulties living in these contexts. Although there is a critical need for specialised services such as AAC, currently there is inadequate research conducted on AAC in low- and middle-income countries (Srinivasan, Mathew, & Lloyd, 2011). Therefore, to date, there is only a limited understanding of how best to foster the development of knowledge and skills of individuals who provide AAC support in low- and middle-income countries (e.g., Bornman, Alant, & Lloyd, 2007; Crowley et al., 2013; Muttiah, McNaughton, & Drager, 2015).

In low-resource countries similar to Sri Lanka, the use of low-technology AAC options such as pictures, communication books and communication boards, is common. These AAC options are most appropriate for these contexts as they are readily available in any environment, are low-cost and sustainable. In addition, these can be easily developed and implemented by therapists, teachers and parents.

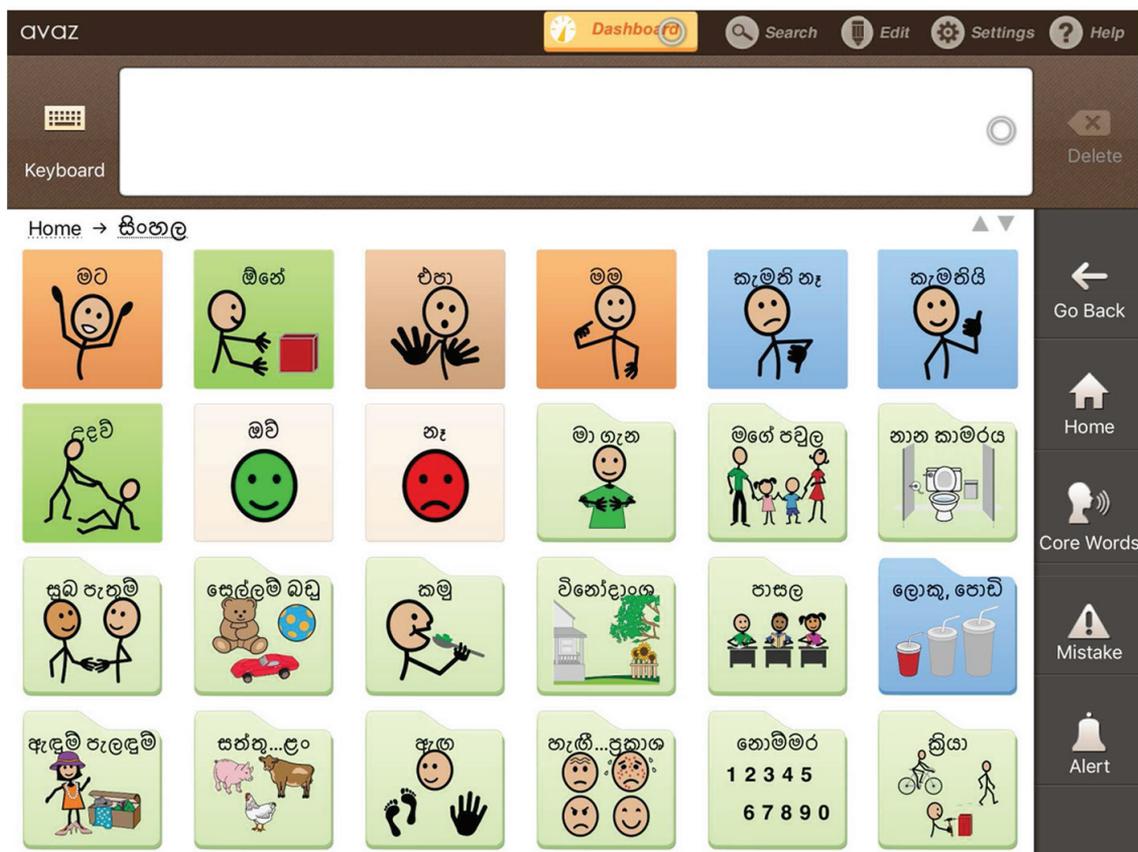
However, the introduction of communication applications on mainstream technologies, such as tablets and mobile phones, has provided new avenues for communication for many individuals with communication difficulties (McNaughton & Light, 2013). Many benefits of using these communication applications have been reported, such as increased functionality (access to education, vocational training and employment) for individuals with communication difficulties (Williams, Krezman, & McNaughton, 2008). In addition, there is a large research base on how the use of such communication applications has resulted in increasing the communication abilities of individuals with communication difficulties (e.g., Ganz, Hong, Goodwyn, Kite, & Gilliland, 2015; Gevarter et al., 2014). These types of communication applications are accessed through a mobile phone or tablet and when children touch the pictures or words on the device, the name of the symbol that was touched is spoken aloud. The speech that is produced through the application is usually digitised speech but many communication apps have options to record a voice as well. For example, if the child wants to eat, he/she can touch pictures/words on the app to say "I'm hungry", or if the child wants to answer a question in school, he/she can touch the communication application to provide an answer. Similarly, an adult with developmental disabilities can use this to communicate with his/her colleagues at his/her place of employment. Individuals with communication difficulties can be

taught to use these communication applications to communicate their thoughts and a variety of messages.

Using these types of high-tech computer-based AAC options may not be viable in low- and middle-income countries. The reasons are the high expenses associated with purchasing a tablet computer or mobile phone, the lack of culturally and linguistically appropriate communication applications to suit the needs of that population (Soto & Yu, 2014), and the limited number of trained clinicians who may be familiar with using these types of AAC solutions (Kieling et al, 2011). However, there is a small but growing body of evidence demonstrating success in the use of these types of high-tech AAC options in low- and middle-income countries (e.g., An et al., 2017; Genc-Tosun, D., & Kurt, O., 2017; Tönsing, 2016).

In November 2017, the first communication application developed in Sinhala and Tamil (local languages), Avaz Sri Lanka, was launched in the country (Muttiah, 2018). Avaz Sri Lanka allows children with severe communication difficulties, including those with ASD, to express their needs and wants, build social relationships, and participate in education and society. More research is needed on this communication app to identify its compatibility with the development of typical language, to gauge children's success with learning to use this app, and assess how easily therapists, teachers and parents can be trained to facilitate using the app with children who have communication difficulties (see Figure 1).

Figure 1: Avaz AAC for Sri Lanka (a screenshot of the application)



In Conclusion

The path for children with ASD and their families in Sri Lanka has not been easy. However, in the past decade there has been a significant increase in awareness of ASD, with more children accessing services, an increased number of healthcare workers intervening with these individuals, more schools accepting children with ASD, increased access to AAC solutions (e.g., Avaz Sri Lanka) and a growing body of research on ASD in Sri Lanka. The road ahead is still challenging for these children and their families. However, the achievements of the past 10 years should give them hope and should inspire clinicians and researchers to do more on their behalf. The journey ahead is long and arduous but positive strides are being made.

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